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No. 88-1503

IN THE
Supreme Court of the United States
OCTOBER TERM, 1989

NANCY BETH CRUZAN, by her parents and co-guardians, LESTER L. and JOYCE CRUZAN,
Petitioners,

v.

DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, and ADMINISTRATOR OF THE MISSOURI REHABILITATION CENTER AT MOUNT VERNON,
Respondents,

v.

THAD C. MCCANSE, Guardian ad litem,
Respondent.

On Writ of Certiorari to the Missouri Supreme Court

JOINT BRIEF OF AMICI CURIAE, THE AMERICAN NURSES ASSOCIATION AND THE AMERICAN ASSOCIATION OF NURSE ATTORNEYS IN SUPPORT OF PETITIONERS

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INTEREST OF AMICI CURIAE [1]

American Nurses Association:

The American Nurses Association (ANA) is an association of registered nurses that is dedicated to the advancement of the goals and interests of registered

[1] The parties to this case have consented to the filing of this amicus brief. The letters providing consent have been filed with the Clerk of this Court.

nurses and of the nursing profession generally. It was founded in 1897 to promote the professional and educational advancement of nurses and to establish and maintain a code of ethics for the nursing profession. The ANA currently represents the 2.1 million registered nurses in the United States and its territories through its 53 constituent member organizations. The ANA establishes professional standards for nursing practice, nursing education, nursing services and a code of ethical conduct for nurses. Through the code of ethics, the ANA is mandated to work for the improvement of health standards and the availability of health care to all persons, regardless of their social or economic status, lifestyle or individual value system, or nature of their health problems.

The American Association of Nurse Attorneys:

The American Association of Nurse Attorneys (TAANA) is a voluntary non-profit professional association whose members have combined the professions of nursing and law. Established in 1982, its membership is comprised of individuals who hold professional degrees in both nursing and law, or have completed the requirements for one profession and are actively pursuing a professional degree in the other. It's membership presently numbers over 500. TAANA is dedicated to the education of nurses on legal issues relevant to the profession. It is also committed to educating the public and members of the legal profession about the nature and standards of nursing practice.

Interest of Amici:

The ANA's and TAANA's interest in the present case is related to the unique role of registered nurses in the provision of health care. "There is no other professional provider in the hospital or nursing home who has the continuous relationships with patients that characterizes

nursing practice." [2] The continuous presence of the nurse and the intimate nature of nursing care create a sensitivity to client needs and concerns, including the needs demonstrated by the petitioner. In the case of individuals in a persistent vegetative state who can do nothing for themselves, it is the nursing staff who must meet the client's physical needs, protect the client's dignity and provide emotional support for the family.

Registered nurses constitute the largest group of health care providers in this country; presently numbering 2.1 million. The Code of Nurses [3] recognizes that autonomy in decisions affecting personal health care is fundamental to respecting the human dignity of each client. As client advocates, nurses are ethically bound to assist the client in maintaining control over his or her individual life in order to assure the client's dignity and self-esteem. The decision of the Missouri Supreme Court has created a tension between the law as found by the court and the ethical obligations of the nursing profession. The outcome of this case on appeal will directly affect the professional services provided by members of the nursing profession and the clients they serve. Accordingly, *amici* wish to present their views concerning the issues presented on appeal.

The *amici* are joined in this brief by the New Jersey State Nurses Association, the Missouri State Nurses Association, the American Association of Critical-Care Nurses, and the Emergency Nurses Association.

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[2] Statement of Lucille Joel, ANA President, to the President of the Joint Commission on Accreditation of Healthcare Organizations, reported in *The American Nurse*, June 1989 at pg 26.

[3] Code for Nurses with Interpretive Statements, ANA, 1985.

SUMMARY OF ARGUMENT

The right to decide for one's self whether to submit to medical treatment is a fundamental interest, deeply rooted in this nation's history, and stringently guarded from state interference by the Constitution of the United States. The Missouri Supreme Court held that this right to personal autonomy and self-determination in health care was outweighed by the state's interest in the preservation of life in the case of the incompetent before the court and similarly situated individuals. The decision below has a very broad reach, and makes no attempt to narrow its application to those situations where there is no reasonable basis for determining what the incompetent individual would decide.

The decision of the Missouri Supreme Court not only violates the constitutional rights of incompetent patients with no hope of recovery, but would require professional nurses to violate the most fundamental ethic of nursing practice—the obligation to ascertain and carry out the wishes of the patient, whether competent or incompetent, in all situations. It ignores the nurse's role as patient advocate, and the ability of the nurse in collaboration with other health care providers to adequately protect the state's interest in the preservation of life. The *amici* therefore urge this Court, for the reasons which follow to reverse the decision below, and to grant the relief requested by the petitioner herein.

ARGUMENT

I. THE DECISION BELOW VIOLATES THE MOST FUNDAMENTAL RIGHT TO PERSONAL SECURITY AND AUTONOMY WHICH IS PROTECTED BY THE FOURTEENTH AMENDMENT TO THE CONSTITUTION

A. The Right to Autonomy and Security in One's Own Person Is a Fundamental Right

In a 4-3 decision over vigorous dissent, the Missouri Supreme Court decided that Nancy Cruzan, an incompetent patient with a close and loving family, no longer has the right to refuse continued medical intervention which keeps her body functioning. The majority supported its decision by drawing distinctions rejected by other courts, relying upon medical "facts" that are not borne out by the testimony or medical evidence, and finding an "unqualified state interest in the preservation of life". *Cruzan by Cruzan v. Harmon*, 760 S.W.2d 408, 420 (Mo. banc, 1988). The right to personal security is a fundamental right which long pre-dates the Constitution and is inviolate unless and until the rights of an innocent third party may be affected.

In Blackstone's Commentaries, 1:125, 136 (1765), he wrote that the right of security in one's person is one of the three "principal absolute rights of every [person] . . . which are founded on nature and reason . . .", which are "fundamental laws" and which may not "be sacrificed to public convenience". This right of personal security includes the right ". . . to the preservation of a man's health from such practices as may prejudice or annoy it." *Id.* at 130. These rights were first guaranteed to the people of England under King John's Great Charter of Liberties in the Thirteenth Century A.D. They are not the creation of the Constitution. To the contrary, the protection and preservation of these important natural rights is the *raison d'etre* of the Constitution.

> For the principal aim of society is to protect individuals in the enjoyment of those absolute rights, which were vested in them by the immutable laws of nature; . . . and are usually summed up in the one general appellation, and denominated the liberty of mankind.

Blackstone, *supra*, at 1:120-21. While this Court has hesitated to protect the right to privacy based upon a "natural law" approach,[4] the right to be free from unconsented medical treatment is clearly a fundamental right.

The Constitution was ordained and established to "secure the Blessings of Liberty to ourselves and our posterity". U.S. CONST., Preamble. The liberty thus guaranteed "without doubt . . . denotes freedom from bodily restraint, . . . to marry, to establish a home and to bring up children . . . and generally to enjoy those privileges long recognized at common law as essential to the orderly pursuit of happiness by free men." *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923).

The fundamental nature of the individual's right to be free from unconsented medical treatment was recognized by this Court as early as 1891. In holding that a claimant in a personal injury suit could not be forced to undergo a physical examination without her consent, this Court stated that:

> "[N]o right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession of his own person, free from all restraint or interference by others, unless by clear and unquestionable authority of law."

Union Pacific Railroad v. Botsford, 141 U.S. 250, 251 (1891). Whatever the specific Constitutional language under which this right is recognized, the interest in freedom from unconsented medical care is *more* personal and

[4] See, *Griswold v. Connecticut*, 381 U.S. 479, 499 (1965) (Harlan, J. concurring).

less likely to affect the rights of third parties than the rights to freedom of choice in marital decisions,[5] child bearing,[6] and child rearing.[7] The Court below relied upon *Bowers v. Hardwick*, 478 U.S. 186 (1985) (upholding the constitutionality of a state statute prohibiting sodomy) to disavow the existence of a fundamental right in this case. *Cruzan*, 760 S.W.2d at 418. Unlike the conduct in question in *Bowers*, however, the right to control one's person, particularly in regard to health care free from unwanted interference by the state, is "deeply rooted in this Nation's history and tradition" and "implicit in the concept of ordered liberty". 478 U.S. at 190-91.

The right of the individual to self-determination in health care has been recognized by virtually every court which has addressed the issue. *E.g., Gray by Gray v. Romeo*, 697 F.Supp. 580 (D.R.I. 1988); *Matter of Jobes*, 529 A.2d 434 (N.J. 1987); *In re Gardner*, 534 A.2d 947 (Me. 1987); *Rasmussen by Fleming v. Mitchell*, 741 P.2d 674 (Ariz. 1987); *Brophy v. New England Sinai Hospital, Inc.*, 497 N.E.2d 626, 633 (Mass. 1986); *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. App. 2 Dist. 1986). Nancy Cruzan's fundamental right to be free from unconsented medical care has clearly been infringed by the State of Missouri. If the decision below is allowed to stand, the state will be allowed to pursue unchecked, its policy of holding incompetent patients hostage through medical technology, irrespective of their wishes.

B. The Fundamental Right to Autonomy and Self-Determination Overrides the State Interest in the Preservation of Life

The Missouri court acknowledged a common law right to refuse treatment that is "not absolute" and which may

[5] *Broddie v. Connecticut*, 401 U.S. 371 (1971); *Loving v. Virginia*, 388 U.S. 1, 12 (1967).

[6] *Skinner v. Oklahoma*, 315 U.S. 535 (1942).

[7] *Pierce v. Society of Sisters*, 269 U.S. 510, 535 (1925); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923).

not be exercised by the parents of an incompetent patient in accordance with their belief as to what she would decide if she could. The court held that despite the unanimity of medical opinion regarding Nancy's medical condition, consent of the guardian ad litem, and court approval following a full hearing of the issues, the gastrostomy tube could not be withdrawn. *Cruzan*, 760 S.W.2d at 421. In reaching its decision, the court focused upon Nancy's inability to give informed consent to the withdrawal of the artificial nutrition, since she is not capable of making a personally informed decision. Yet, at the time consent was given to surgically implant the feeding tube, she was no more capable of personally giving informed consent than at the present time. The Missouri court totally ignores this aspect of the case, although it starts from the premise that "a decision as to medical treatment must be informed." *Id.* at 417. The court below rationalized that since the insertion of the gastrostomy tube has already been accomplished, albeit without Nancy's consent, consent is not required to continue the "introduction of food and water" through the tube. *Id.* at 422-23.

The court below failed however to recognize that the continuance of tube (enteral) feedings is not without risks of complications. *See* Konstantinides, N. and Shronts, E., "Tube Feeding: Managing the Basics", *American Journal of Nursing*, 1312, 1319-20 (Sept. 1983). Complications associated with tube feeding include mechanical, metabolic and gastrointestinal problems, some of whch may be life-threatening. *Id.* The risks of complication from enteral therapy are not the only potential medical problems faced by patients in Nancy Cruzan's condition, however. Constant bedrest alone has a seriously detrimental affect on all the body's major organs. *See*, Rubin, M., "The Physiology of Bedrest", *American Journal of Nursing*, 50 (Jan. 1988).

The right to be free from nonconsensual invasions of one's bodily integrity lies at the heart of the doctrine of informed consent. *E.g.*, *Canterbury v. Spence*, 464 F.2d

772 (D.C. Cir. 1972); *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972). The *Cruzan* court would deny this right where the treatment is deemed to be "not heroically invasive" and the patient is incompetent. 760 S.W.2d at 423. As this Court noted in *Thornburgh v. American College of Obstetrics and Gynecology*, ". . . this is, or comes close to 'state medicine' . . ." being imposed upon those unfortunate persons in Nancy Cruzan's condition. 476 U.S. 747, 763 (1985).

A fundamental right of this magnitude cannot be denied merely because there is no means of obtaining a personally informed consent. *In re Guardianship of Barry*, 445 So. 2d 365, 370 (Fla. Dist. Ct. App. 1984) ("The constitutional right of privacy would be an empty right if one who is incompetent were not granted his rights.") *Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334, 1337 (Del.Ch. 1980) ("[T]o deny the exercise because the patient is unconscious would be to deny the right.") *Matter of Quinlan*, 355 A.2d 647, 664 (N.J.), *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976). ("If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right to privacy . . . then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice.") The Massachusetts Supreme Court has held that the maintenance of a person in a persistent vegetative state for a period of years is intrusive treatment as a matter of law. *Brophy*, 497 N.E.2d at 636.

The position of the majority below ignores the fundamental rights of incompetent individuals who have absolutely no hope of recovering any cognitive function to decide, at some point, to "allow the natural processes of a disease or affliction to bring about a death with dignity." *Id.* This Court has previously recognized that the "law must often adjust the manner in which it affords rights to those whose status renders them unable to exer-

cise the choice freely", noting that "those who are irreversibly ill with loss of brain function . . . retain 'rights' to be sure, but often those rights are only meaningful as they are exercised by agents acting with the best interests of their principals in mind." *Thompson v. Oklahoma*, —— U.S. ——, —— n.23, 108 S.Ct. 2687, 2693 n.23 (1988) (plurality opinion). The *Cruzan* majority purports to protect the right of incompetents to exercise their right to refuse treatment by acknowledging the power of a guardian, but states that the third party may not do so "absent the most rigid of formalities." 760 S.W.2d at 425. It's edict mandating the "formalities required under the Missouri Living Will Statute" [8] or "clear and convincing, inherently reliable evidence absent here" be met renders the Missouri court's position illusory at best.

The court below noted that it is impossible for consent to refuse treatment to be given under "hypothetical circumstances". *Id.* at 417. Since the expression of an individual's wishes as to the termination of treatment, if and when the individual ever were to become incompetent, must necessarily be based upon a hypothetical, nothing less than compliance with the formalities of the Missouri Living Will Statute, *supra*, would ever meet the standards demanded. Since the living will statute precludes the withdrawal of nutrition and hydration in any event, persons cannot utilize the procedures established by the act to give an advance directive to withdraw a feeding tube that will be respected by the Missouri courts. Thus, despite the *Cruzan* majority's note that "[t]his is not a matter of a forfeiture of a constitutional right because that term implies some state action which deliberately removes or limits a constitutional right", 760 S.W.2d at 418 n.14, the constitutional rights of Nancy Cruzan, and all others similarly situated are clearly implicated.

"A person has a paramount right to control the disposition to be made of his or her body, absent a com-

[8] Mo.Rev.Stat. sec. 459.010 *et seq.*

pelling countervailing governmental interest." *Gray by Gray*, 697 F.Supp. at 585, *citing*, *Tune v. Walter Reed Army Medical Hospital*, 602 F.Supp. 1452, 1454 (D.D.C. 1985). A state law which infringes a fundamental right is presumptively unconstitutional. *Mobile v. Bolden*, 446 U.S. 55, 76 (1980). As John Stuart Mill explained,

> [T]he only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because in the opinion of others, to do so would be wise or even right.

Mill, J., "On Liberty", 43 *Great Books of the Western World* 271 (R. Hutchins ed. 1952).

The decision below was not premised upon the necessity to protect the rights of third parties, but upon a nebulous state interest in the preservation of life expressed in the subsequently enacted living will statute. The majority did not attempt to find a means to protect the rights of incompetents who would not wish to continue a vegetative existence in the face of a hopeless prognosis. To the contrary, the court held that the state's strong interest overrides "any rights invoked on Nancy's behalf to terminate treatment", period. *Cruzan*, 760 S.W.2d at 426. The interest of the state and the "formalities" required by the majority do not withstand review under the compelling state interest test in this situation. Not only must the state interest be compelling as a matter of law, but any limitations imposed by the state upon the exercise of a fundamental right must be narrowly drawn and reasonably related to the legitimate state interest at stake. *E.g.*, *Griswold v. Connecticut*, 381 U.S. at 485; *Shapiro v. Thompson*, 304 U.S. 618 (1963).

The Missouri court attempts to protect the rights of incompetent patients who would choose to continue treatment in an extremely broad manner, and without regard to the rights of those who would choose to terminate the treatment.[9] Allowing the state to take any option away from incompetent patients by default cannot withstand constitutional muster. The court must fashion a procedure for surrogate decision making which will recognize the patient's rights, and to the maximum extent feasible assure that the patient's wishes are given effect.

Every court that has considered the issue has been able to develop a mechanism and standards which it was confident would protect the rights of the incompetent without compromising legitimate state interests.[10] While the courts are not in complete agreement as to the exact procedures to be followed, the courts have unanimously found that the rights of the incompetent outweigh any countervailing state interest in the preservation of life. *E.g., Gray*, 697 F.Supp. at 589 (the continued use of a gastrostomy tube against the incompetent's wishes as determined by her family and a court appointed guardian ad litem, robs her of the right to self-determination in her medical care, which outweighs the state's interest in the preservation of life for all); *Brophy*, 497 N.E.2d at 635 (duty of state to preserve life must recognize individual's right to avoid circumstances in which the individual himself would feel that efforts to sustain life demean or degrade his humanity); *Matter of Peter by Johanning*, 529 A.2d 419, 427 (N.J. 1987) (the court finds it "difficult to conceive of a case in which the state could have an interest strong enough to subordinate

[9] This decision cannot be viewed in a vacuum. The impact upon other incompetent PVS patients must be considered given the breadth of the holding below.

[10] See, bibliography of cases compiled by the majority in *Cruzan*, 760 S.W.2d at 412 n.4.

a patient's right to choose not to be artificially sustained in a persistent vegetative state). In cases of temporary incompetency due to medical conditions, patient's families routinely make decisions for the incompetent, without judicial involvement of any nature.[11]

The ethical integrity of health care providers is respected and protected by the courts. The New Jersey Supreme Court has specifically recognized that the state interest in the preservation of life is sufficiently protected by the ethical, moral and legal obligations of physicians and other health care personnel. *Id.* at 448 n.15. *Matter of Jobes*, 529 A.2d at 448. The ANA Code requires the nurse

> [a]s advocate for the client . . . [to] be alert to and take appropriate action regarding any instances of incompetent, unethical, or illegal practice by any member of the health care team or the health care system, or any action on the part of others that places the rights or best interests of the client in jeopardy.

ANA Code, *supra*, at 6. The Code also requires nurses to "take all reasonable means to protect and preserve human life when there is hope of recovery or reasonable hope of benefit from life-prolonging treatment." *Id.* at 2. The mandate of the nursing profession's code of ethics in conjunction with the similar obligations of other members of the health care team[12] assures that the governmental interest in the preservation of life will be protected, at the same time that the rights of incompetent patients are preserved.

[11] It is reported that "on an average about 10 life support systems are disconnected weekly in Minnesota." *Matter of Conservatorship of Torres*, 357 N.W.2d 332, 341 n.4 (Minn. 1986). The President's Commission Report states that life supporting treatment is withdrawn from many of the nation's permanently unconscious patients. *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment*, at 176-77 n.15 (1983).

[12] *E.g., see* brief of *amicus curiae* the American Medical Association.

The Missouri court reached a decision below which is diametrically opposed to virtually every other judicial opinion on the issue. In weighing the benefits and burdens of continuing the treatment, the court conveniently ignored pertinent medical facts to achieve its objective. In conclusory terms, the court finds that Nancy's current condition and total care requirements are not sufficiently burdensome to her to outweigh the state's interest in the preservation of life. *Cruzan*, 760 S.W.2d at 424. It is significant to note that the court omitted mention of any countervailing benefit to Nancy.[13] The position of the Missouri court totally ignores the individual's right to maintain human dignity even in the absence of mental awareness. Nancy lies helplessly in bed, with no control over her intimate bodily functions. She must be bathed and have her bowel and bladder functions taken care of by strangers. Her extremities are so permanently flexed from the combined effect of brain damage and muscular contractures that she lies in what is approaching a fetal position, unable to turn or move on her own. Even with assistance she can no longer straighten her arms or legs. Her wrists and elbows are so contracted that her fingernails grow into her wrists and forearms. For a woman who was outgoing and independent, 760 S.W.2d at 432, the impact of her condition on her dignity must be given consideration, even though she is no longer competent, *e.g.*, *Brophy*, 497 N.E.2d at 635.

C. Where the Patient Is Incompetent, His Wishes Will Most Likely Be Effectuated by the Family in Collaboration With the Health Care Team

This court has long recognized that there is a "realm of family life which the state cannot enter" without substantial justification. *Prince v. Massachusetts*, 321 U.S.

[13] The Hastings Center Report finds that "the only possible benefit to [patients who are permanently unconscious] of life-sustaining treatment is the possibility that the diagnosis of irreversible unconsciousness is wrong and they will regain consciousness." *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*, 29 (The Hastings Center, 1987) (hereinafter "Hastings Center Report").

158, 166 (1943). Justice Stevens has summarized the privacy decisions as recognizing the right of individuals to make "certain unusually important decisions that will affect his own, or his family's destiny," *Thornburgh*, 476 U.S. at 781 (concurring opinion). Surely no decision subsequent to one's birth is more important than the manner of one's death, when faced with a choice. The special role of the family in the case of incompent individuals has been firmly established by the courts, the healing professions and the nation's leading ethicists.

> "Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patients approach to life, but also because of their special bonds with him or her. Our common human experience informs us that family members are generally most concerned with the welfare of a patient. It is they who provide for the patient's comfort and care, and best interest, and they who treat the patient as a person rather than a symbol of a cause."

In Re Jobes, 529 A.2d at 445.

Where an individual lacks the capacity to make his or her own informed health care decisions, ". . . the responsibility rests on those presumed to know what the person would desire. . . .". Dufault, K., "What is Nurse's Role When Adults Forego Treatment?", *Ethical Dilemmas Confronting Nurses*, 9 (ANA Committee on Ethics, 1985). In the present case, all of the extensive medical care and numerous invasive procedures Nancy has been subjected to were consented to by her husband and parents without court involvement. Following an extensive study of the issues involved, The Presidents Commission concluded:

> The decisions of patients' families should determine what sort of medical care permanently unconscious patients receive. Other than requiring appropriate decisionmaking procedures for these patients, the law does not and should not require any particular therapies to be applied or continued, with the excep-

> tion of basic nursing care that is needed to ensure dignified and respectful treatment of the patient.

President's Commission Report, *supra* at 4-5. Where the patient has left no advance directive, the goal in identifying a surrogate decision maker must be "to find the person who is most involved with the patient, and most knowledgeable about the patient's present and past feelings and preferences. *Hastings Center Guidelines*, *supra*, at 24.

By virtue of the amount of time spent with the client and the client's family, the nurse is in a unique position to identify the most appropriate surrogate in a particular case, and to be aware of the wishes of the incompetent. See, Cowles, K. and E. Murphy, *Nursing Practice in the Care of the Dying*, 10 (ANA, 1982). The court in *Matter of Jobes* found that surrogate decision making by the families of incompetent patients is strongly supported by public opinion. 529 A.2d at 446. The patients' wishes remain paramount, and in the case of the incompetent adult, it is the family who is most likely to know what those wishes would be. *Id.* Thus, the family in collaboration with the nurse and other members of the health care team is the most appropriate surrogate decision maker in those cases where the incompetent patient is fortunate enough to have a close and loving family.

II. THE DECISION BELOW WOULD REQUIRE PROFESSIONAL NURSES TO VIOLATE THE FUNDAMENTAL PRINCIPLES OF NURSING PRACTICE

A. The Nurse Is Required to Be an Advocate for Her Clients

The ANA Code for Nurses with Interpretive Statements states in its Preamble:

> The Code for Nurses is based upon a belief about the nature of individuals, nursing, health and society. Nursing encompasses the protection, promotion and restoration of health; the prevention of illness; and the alleviation of suffering in the care of clients including individuals, families, groups and communities. In the context of these functions, nursing is defined as the diagnosis and treatment of human responses to actual or potential health problems.
>
> Since clients themselves are the primary decision makers in matters concerning their own health, treatment, and well-being, the goal of nursing actions is to support and enhance the client's responsibility and self-determination to the greatest extent possible.
>
> ANA Code at i.

The ANA Code was first adopted in 1950, formalizing the basic philosophical values of the nursing profession. Its principles ". . . are not open to negotiation in employment settings. . .". *Id.* at iv.

The nurse's role as an advocate for her patients has long been recognized by the profession. Reference to this role appears early in the nursing literature. "The nurse . . . is the picket-guard. On her care and watchfulness the well-being of the patient very largely depends. Riddle, M., "Prophylactics", *American Journal of Nursing*, 1:40 (Oct. 1900). The nurses obligation to safeguard the client's moral right to self-determination will be seriously undermined if the decision below is allowed to stand.

"The fundamental principle of nursing practice is respect for the inherent dignity and worth of every client". ANA Code at 2. Every person is the product of a different collection of experiences and realities that make him or her an individual, with a unique perspective. Respect for the individual requires an evaluation of that person's values as reflected in his lifestyle, religious values, priorities and opinions. *See*, Cowles, *supra* at 3. The decision of the Missouri Supreme Court would require nurses to disregard the client's wishes, by requiring every person to be treated identically despite his or her unique per-

spective. The decision below thus ignores the dignity of the individual.

The ANA recognizes that it is morally permissible to withhold food and fluid at the request of a competent, reflective adult. *Guidelines on Withdrawing or Withholding Food and Fluid*, ANA Committee on Ethics, Jan. 1988. Although the issue is clearly more difficult when the patient is no longer competent, the nurse is still required to respect the client's wishes "when it is possible to establish with certainty the patient's projected refusal." *Id.* at 2. The Guidelines recognize that appropriately validated advance directives may be "aids in discerning the patient's view." Likewise, the opinions of the family as the persons most likely to be familiar with the incompetent individual's values and preferences, should be taken into consideration.

> The application of a previously stated refusal will, of necessity, require judgment—both clinical and moral—of nurses and other caregivers as to whether the current situation is one to which the patient intended her or his refusal to apply. In general, Advance Directives, even those involving the withholding or withdrawing of food and fluid should carry great weight in caregiver's discussions with the patient's family or surrogate. It is imperative, in this process, that nurses not substitute their own views about which lives are worth saving and living for the views of their competent or formerly competent patients.

Id.

The withholding or withdrawing of food and fluid does not terminate all care the client had been receiving. To the contrary, while medical treatment may be terminated, nursing care must continue. *Nursing Practice in the Care of the Dying, supra*, at 10.

> When the choice is made to forego life-sustaining treatments, greater emphasis is placed on human

> contact. Care is then directed toward prevention and relief of the suffering commonly associated with the process of dying. Nursing care will determine to a great degree how this final experience is lived and the peace and dignity with which death is approached.

Dufault, "What is the Nurse's Role When Adults Forego Treatment", *supra*, at 10. Most nursing measures are of a supportive and caring nature. The measures that would appropriately be continued where a decision has been made to withdraw food and fluids include skin care and turning to prevent skin breakdown; mouth care to keep the mouth clean, mucous membranes moist and lips from cracking or blistering; keeping the bed linen clean and dry and otherwise maintaining patient hygiene and comfort. *See, Conservatorship of Drabick*, 245 Cal. Rptr. 840, 845 (Cal. App. 6 Dist. 1988).

B. The Rights of the Providers to Practice in Accordance With Ethics and Standards of Nursing Practice are Entitled to Protection

Much has been written and the courts have long recognized the preservation of the ethical integrity of the medical profession as a legitimate consideration in the balancing of individual rights in health care matters against the interests of the state. *E.g.*, Gray, 697 F. Supp. at 588; *Brophy*, 497 N.E.2d at 634; *Hastings Center Guidelines*, *supra* at 19-20. The *Cruzan* court, together with virtually all other courts addressing the issue of withdrawal of life-sustaining treatment has recognized this interest. 760 S.W.2d at 419. Ethical concerns in the provision of health care services are not limited to the medical profession. The care of patients in a persistent vegetative state is primarily *nursing care*, not medical care. It is the nurse who spends the many hours at the patient's bedside, while the physician may stop in to check on the patient on a daily basis, or even less frequently in the case of longterm patients with chronic conditions. Thus, the courts must also recognize and protect the ethical integrity of the nursing profession.

Nursing was the first professional group to issue a statement recognizing patients rights, in 1959. "What People Can Expect of Modern Nursing Practice", *Position Statement* (National League for Nursing, 1959). The patient's right to autonomy and self determination in health care decisions is now widely recognized by health care institutions, in the form of a patient's Bill of Rights. The American Hospital Association (AHA) issued its first "Statement on a Patient's Bill of Rights" in 1973. Many organizations and some states have subsequently followed the lead of professional nursing in recognizing and mandating that patients be afforded their fundamental rights in healthcare facilities. *E.g.*, "A Model Patient's Bill of Rights", American Civil Liberties Union; Policy and Statement of Patients' Choices of Treatment Options", AHA 1985; CAL. ADMIN. CODE, sec. 70707 (West). Uniformly, these patient's rights statements recognize the right to autonomy and self determination in deciding whether to undertake or forego medical care. Nurses practicing in these institutions are entitled to follow these precepts which the profession was so instrumental in developing.

The *Cruzan* majority would require the nurse to violate the most fundamental moral principle which prescribes and justifies nursing actions: respect for individuals and their personal autonomy. The state interest in maintaining the ethical integrity of the nursing profession requires that the decision below be reversed.

III. THE ISSUE BEFORE THIS COURT CANNOT BE ISOLATED FROM ITS POTENTIAL IMPACT UPON THE HEALTH CARE SYSTEM

The opinion of the *Cruzan* majority creates numerous public policy concerns without addressing any potential resolutions. While courts generally refrain from deciding questions not directly before them, the decision in this matter cannot be totally divorced from the potential consequences and underlying policy concerns. Many courts which have addressed the issue presented have done so against challenges of mootness because of the intervening death of the incompetent individual whose rights are in question. *E.g.*, *Rasmussen*, 741 P.2d at 680; *c.f. Matter of Conroy*, 486 A.2d 1209 (N.J. 1985). These courts have nevertheless heard the case as one which is "capable of repetition yet likely to evade review". In this situation, where the rights of many individuals are likely to be affected before this court has another opportunity to address the issue, the policy questions must be given consideration, and guidance given to the lower courts.

The allocation of increasingly scarce health care resources, while an unpleasant subject, is a policy issue which cannot be ignored. It was reported in 1987 there are between 5,000 to 10,000 persons in a persistent vegetative state in this country at any one time, and the number is expected to increase. Cranford, R., M.D. and Smith, D., J.D., "Consciousness: The Most Critical Moral (Constitutional) Standard for Human Personhood", 13 *American Journal of Law and Medicine*, 231, 238 (1987). The Massachusetts Supreme Court found that Mr. Brophy received 7.5 hours of nursing care per day to meet his basic needs. 497 N.E.2d at 631. The federal Medicare program presently pays for only 3.5 hours of nursing care per day, but only if skilled nursing care is required, and then, only for 150 days per year. *The Medical Handbook*, U.S. Dept. of Health and Human Services at 10-11 (1989).

Nancy Cruzan lies in a state institution, and the court below found that the state of Missouri "is apparently willing to maintain Nancy as long as she lives without expense to her parents or others". *Cruzan*, 760 S.W.2d at 427. Her care is reported to cost the state of Missouri $130,000.00 per year. *See*, Petitioner's Brief, Statement of Facts. There is a serious question whether the state of Missouri has actually allocated sufficient resources to

to provide care to Nancy that meets accepted nursing standards however, the fact that her contractures are still progressing raises concern of professional nursing as to whether every nursing measure that can be taken to maintain her comfort and dignity has been taken.

Not all patients similarly situated as Nancy Cruzan are in state institutions. When the private insurance, if any, runs out, who will pay? The American Hospital Association has reported that in 1988, eighty-one U.S. community hospitals closed. *The American Nurse*, March 1989 at 11. A major reason for the closures is inadequate Medicare and Medicaid payments for services rendered to the elderly and the poor. In recent years, seven out of ten rural hospitals and fifty percent of the nation's urban hospitals have lost money. *Id.* Judge Blackmar, in his dissent below has pointed out that the State of Missouri has not shown a willingness to "finance the preservation of life, without regard to cost" in very many cases. *Cruzan*, 760 S.W.2d at 429.

Many courts addressing the withdrawal of life-sustaining treatments have recognized serious policy concerns in regard to precluding the withdrawal of treatments which may legally and morally be withheld in the first instance. Will the prohibition encourage patients, their families and health care providers to decide not to start enteral therapy, or to refuse consent to surgically implant a feeding tube in the fear that they may thereafter be legally mandated to continue the treatment even though no hope of recovery or long-term improvement remains? The Massachusetts Supreme Court pointed out that these decisions are becoming more difficult as the medical profession has begun to realize that life-sustaining measures in many cases serve only "to prolong suffering, isolate the family from their loved one at a time they may be close at hand or result in economic ruin for the family." *Superintendent of Belchertown v. Saikowitz*, 370 N.E.2d 417, 423 (1977).

CONCLUSION

The *amici* herein have no answers to these difficult policy issues. Nonetheless, they are questions which nurses and other health care providers will face with increasing frequency if the decision below is allowed to stand. For the reasons set forth above, the *amici* urge this court to recognize and give effect to the rights of incompetent patients to autonomy and self-determination in health care decisions, to support the ethical values of the nursing profession and allow health care providers to determine and carry out the wishes of incompetent patients in collaboration with families or other appropriate surrogate decision makers.

Respectfully submitted,

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